IDENTIFICATION AND DEVELOPMENT OF INDIVIDUALIZED ACCESS PATHWAYS BASED ON RESPONSE EFFICIENCY THEORY

by

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A thesis submitted in conformity with the requirements for the degree of Master of Health Science in Clinical Engineering Graduate Department of Institute of Biomaterials and Biomedical Engineering University of Toronto

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Abstract

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2011

Assistive technology (AT) can be defined as any item, piece of equipment or system that is used to increase, maintain or improve the functional capabilities of individuals with disabilities [36] . Despite the evident advantages, many assistive technologies are still abandoned within the first few months of use. The key to changing this may lie in the assessment process, which has been described as the most consequential phase in the provision of assistive technology [14]. The purpose of this research was to create a protocol for the assessment and delivery of individualized access technologies based on the concepts of response efficiency theory. The protocol was applied with three children, ages 12 to 14, who were seeking new access technologies. The results suggest that a protocol based in the theory of response efficiency will result in a technology that is appropriate to the user, and as a result will be less likely to be abandoned and will contribute to goal achievement and potentially improve participation.
Acknowledgements

Special thanks to Dr. Tom Chau for all of his support throughout this process. His guidance, expertise and encouragement were what made this project possible.

Thanks also to my committee members, Dr. Virginia Wright and Dr. Alex Mihailidis, for their insights and advice.

Finally, thanks go out to all of the members of the PRISM lab for their support and encouragement, and in particular to Ka Lun Tam and Pierre Duez who make the impossible, possible.
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Chapter 1

Introduction

1.1 Motivation

Assistive technology (AT) can be defined as any item, piece of equipment or system that is used to increase, maintain or improve the functional capabilities of individuals with disabilities [36]. This includes everything from hearing aids and wheelchairs to devices that can be used for communication and expression. These systems have the potential to greatly enhance the lives of users by increasing the level of autonomy with which they participate in daily activities [39]. Access to computers alone has been shown to increase time spent in therapeutic activities, enhance social participation and improve quality of life [23]. However, despite the evident advantages, many assistive technologies are still abandoned within the first few months of use. In the U.S., average AT abandonment rates of 29% have been reported, with user dissatisfaction in the areas of performance, effectiveness, reliability, durability, comfort and ease of use cited as major contributing factors [36]. As evidenced throughout the literature, successful AT retainment and use is ultimately dependent on achieving a good contextual fit [36]: a good match between the technology and all relevant characteristics of the user, their environment and the individuals who support them [19, 18]. A good contextual fit is an essential underpinning
to the successful adoption of AT. Johnston et. al. have proposed that by applying the concept of response efficiency in the development of assistive technology, a better contextual fit between user and usage, can be achieved and the likelihood of AT abandonment diminished [18].

The purpose of this research was to use the concept of response efficiency theory to create a standardized, access technology delivery protocol, and to use this protocol to develop individualized access technologies and investigate the outcomes.

1.2 Objectives

1. To use the concept of response efficiency to create an Access Technology Delivery Protocol, that includes an assessment process for identifying and developing individualized access pathways.

2. To apply this protocol to several individuals and determine if the resulting technology is more response efficient than the previous means of access.

3. To determine if this framework results in an input device that is appropriate to the user, as defined by ISO 9241-9, and is not abandoned.

4. To examine if and how an appropriate access pathway, with all other variables left uncontrolled, may affect broader aspects of goal achievement and participation for the user and caregiver through a series of recognized participation and outcomes measures.

1.3 Chapter Roadmap

The fulfillment of the thesis objectives is addressed in Chapters 2 and 3. Chapter 2 begins with background information on response efficiency theory, access technologies, and
assistive technology provision, including information regarding current methods, criticisms and recommendations. The chapter goes on to describe the development of a novel assessment and measurement protocol, the Assistive Technology Delivery Protocol (ATDP), and the results of its application with a single subject. In its first application, the ATDP showed overall positive results, and thus we sought to test it with more participants. Chapter 3 further develops the information presented in Chapter 2, describing the application of the ATDP with an additional two subjects. The two subjects described in Chapter 3 are distinctly different both from each other and the subject described in Chapter 2, in terms of health, background, severity and types of disabilities. As a result, Chapter 3 provides preliminary information on the versatility of the ATDP for use across a varied population. Lastly, Chapter 4 reviews the main contributions of this thesis and directions for future work.
Chapter 2

The Assistive Technology Delivery Protocol

2.1 Abstract

Assistive technologies have the potential to greatly enhance the lives of users, however many are abandoned within the first few months of use [39, 15]. It has been proposed that the likelihood of device abandonment would be diminished if the concepts of response efficiency were applied to the development and implementation of assistive technologies [18]. The purpose of this chapter was to create an assessment and measurement process, based on the concepts of response efficiency theory, and to use the process to develop an individualized access pathway. The Access Technology Delivery Protocol (ATDP) was developed after a review of the literature, and a single participant was recruited for testing. Predicated on the ATDP assessment, a smile based access technology was developed for the participant and evaluated over a four-month follow-up period. At the end of the four months, the new access technology appeared to be more response efficient than the previous means of access. Specifically there was a high rating of satisfaction with the technology, goals set out for the participant were attained, improvements were
seen in the quality of life measure, and the technology was still in use at the end of the study period. This case provides initial evidence to support the use of the ATDP, a response efficiency based protocol, with additional individuals with multiple or severe disabilities to determine its usefulness across this varied population.

2.2 Introduction

In Canada, more than half a million children and youth under the age of 20 have a disability [21]. Assistive devices have the potential to greatly enhance the lives of these individuals by increasing their participation in daily activities [39]. However, despite this potential, many assistive technologies are abandoned within the first few months of use [15]. The key to mitigating abandonment may lie in the assessment process, which has been described as the most consequential phase in the provision of assistive technology [14]. Currently, there is a lack of standardization in the methods used to assess and deliver assistive technologies [14, 10, 5]. Johnston et. al. have proposed that by applying the concept of response efficiency in the development and implementation of assistive technology, a better contextual fit can be achieved between user and usage, and the likelihood of device abandonment diminished [18]. The purpose of this research was to create an access technology-specific assessment and measurement process based on the concept of response efficiency to identify and develop individualized access pathways, and to ascertain the outcomes of applying such a method.

2.2.1 Assistive Technology Prescription

Assistive technology (AT) can be defined as any item, piece of equipment or system that is used to increase, maintain or improve the functional capabilities of individuals with disabilities [36]. Prescribing AT has been described as an intrinsically difficult procedure that is prone to failure [14], and the current prescription process criticized as "fundamentally...
mentally flawed” [15]. Statistics show that the current average rate of abandonment for optional AT devices stands at approximately 30% [15, 37]. These outcomes are generally the result of user dissatisfaction with an inappropriate technology [37] resulting from an ineffective AT assessment [15].

Bernd and Hoppestad have identified many different types of models and instruments for AT assessments have been devised in an attempt to provide better and more appropriate services [5, 15]. However, there is a lack of standardization across the field [15, 10, 5]. This is especially true when working with individuals with multiple and/or profound disabilities. There is consensus in the literature that the current assessment instruments are generally inadequate for this population [15]. Even those instruments based on the most well accepted models for AT assessment (e.g. Matching Person and Technology Model (MPT) [12]) have been challenging to incorporate into rehabilitation practice [5]. Although the MPT tools focus on achieving good contextual fit and positive results have been reported for its use with many individuals with disabilities [38], they and other AT specific tools have been found overly complicated and comprehensive for use with individuals with multiple and severe disabilities [5]. Similarly, hierarchical paradigms for determining the most intuitive means of access may not apply with individuals with multiple disabilities as they may have different predilections as a result of their individual conditions [15]. If research regarding key characteristics for the provision of AT cannot be translated into a method that supports practice and policy, its ability to improve health care systems will remain unrealized [10].

A common theme throughout the literature is the need for assessments to focus on characteristics specific to the individual, the tasks they wish to perform and the environment (including caregivers) in which they will be performing them. Other important success factors for AT provision include: consideration of individual or family goals, consideration of family support systems, sensitivity to cultural issues, a multi-disciplinary assessment team, adequate follow-up, suitable technological features and collecting suf-
ficient information regarding past medical and/or educational history [15, 21, 35]. For individuals with multiple and severe disabilities in particular, Hoppestad recommends that the assessment process be flexible and highly individualized, including both formal and observational testing [15]. Assessments for these individuals cannot rely on a single test or testing instrument, but must include information from multiple sources [15].

Any new assessment method should incorporate as many of these recommendations as possible in order to promote successful AT provision.

2.2.2 Access Technologies

An access technology is a particular type of AT that translates the intentions of a user with severe physical impairments into functional interactions [40]. As seen in Figure 3.1, an access technology is the portion of a larger access solution consisting of an access pathway and a signal-processing unit [40]. Access pathways, when paired with the appropriate user interface, can power anything from wheelchairs to lights and televisions to communication devices [40]. The access pathway, commonly known as a switch, comprises the actual sensors or input devices by which an expression of functional intent is transduced into an electrical signal [40]. The signal-processing unit analyzes the input signal from the pathway and generates a corresponding control signal that drives the user interface [40]. The success of all components in an access solution hinges on identifying an access technology that is well suited to the individual.

2.2.3 Response Efficiency

Response efficiency theory is based on matching theory from the field of applied behavioural analysis [18, 22]. The theory states that when individuals have the opportunity to choose between two or more functionally equivalent alternatives, they will select the option that they perceive as most efficient [18]. Four factors have been identified as having significant influence on an individual’s concept of efficiency [18]:
Chapter 2. The Assistive Technology Delivery Protocol

Figure 2.1: Components of an access solution within the user’s environment [40]

1. Rate of reinforcement - The rate at which the individual sees the desired result, e.g., every time they use the technology, every other time, every third time, etc.

2. Quality of reinforcement - How closely the reinforcement coincides with the user’s expectations e.g., exact match, close match, or complete mismatch.

3. Response effort - The physical and cognitive effort required.

4. Immediacy of reinforcement - The delay, if any, between using the technology and observing the desired result. Although each of these factors contributes to the overall perception of efficiency, their relative weighting can vary from individual to individual, and within individuals, depending on the device or the environment [22, 30].

2.2.4 Assessment Development

Although they have yet to implement it, Johnston and Evans [18] suggest that the application of response efficiency concepts to the assessment process could result in better contextual fit between an intervention and each of the following: characteristics of the
person for whom the intervention was developed, characteristics of the individuals who will implement the plan, and features of the environment within which the intervention will be implemented [19, 18]. Generally, the key characteristics for an effective assessment (as identified in section 2.2.1) are tied to achieving a good contextual fit: specifically, the need to focus on the individual characteristics of the user, the tasks they will be performing, and the environment of use. Additionally, devices that are compatible with the individual and his/her environment will likely have good overall response efficiency. Therefore, we contend that the primary focus in developing a method of assessment for access technologies ought to be on the collection of information pertinent to optimizing each of the four factors influencing response efficiency. This information ought to be gathered from both the user and the caregiver, as both perceptions are equally critical to obtaining good contextual fit. In addition to contextual fit, literature also suggests that a multi-disciplinary team, flexibility, and good follow-up procedures are critical to access technology prescription for individuals with severe disabilities [15, 21].

2.3 Objectives

The objectives of this study were:

1. To create a response efficiency-theoretic assessment process that will inform the identification and development of individualized access pathways;

2. To apply this assessment to a single subject case study and subsequently compare the response efficiency of the resultant technology to that of the previous method of access;

3. To describe the appropriateness (according to ISO 9241-9) of the access technology, and
4. To gauge the usage, goal attainment and quality of life outcomes associated with the introduction of a new access technology.

2.4 Methods

2.4.1 The Proposed Access Technology Delivery Protocol (ATDP)

A novel access assessment, technology selection/development and evaluation protocol has been designed for the purposes of this study to provide a response-efficient access technology. The proposed assessment and follow-up procedure are outlined in Figure 3.2. The 6-stage process was developed as a flexible and generic method for incorporating the concept of response efficiency, as well as measuring the success of the pathway. The actual assessment comprises Stages 1 and 2, while the remaining stages consist of evaluation procedures. In the 16 weeks after the delivery of the new technology, the user is expected to train with their new switch in the activities for which they wish to use it. The majority of abandonment for assistive technologies occurs within the first 3 months of use [36]. Therefore, in incorporating a 16-week follow-up period, we would expect that if the technology were inappropriate it would likely be abandoned during that time.

In order to maintain the flexibility suggested in section 2.2.1, the assessment stage was designed to be conducted primarily through an interview process, with additional information being collected through a Client Information Questionnaire (Appendix A)(modified from [28, 27] to exclude the Health section). The questionnaire collects basic information regarding the physical function, cognition, sensory acuity, motor skills and communication skills of the individual and pinpoints the primary and secondary caregivers. The purpose of the assessment is to determine the needs of the user, in terms of an access technology, such that an appropriate solution can be identified.

The interview portion does not contain a specific question set, but is focused on obtaining as much information as possible about the user and caregivers and what they
would perceive as a response efficient solution. This includes information regarding the current access pathway, reasons for dissatisfaction with that pathway, expectations for how and where the new access technology will be used, and potential access sites that require minimal user effort. For example, during the interview one might learn that the switch will be used in both dark and bright environments. This means that the functionality of the switch must be robust to changes in lighting conditions or the rate and quality of reinforcement could suffer. This interview is conducted (in this case by the researcher) with the user, and as many of their communication partners (i.e. caregivers, teachers and clinicians) as possible. These individuals are most familiar with the user’s needs and abilities, as well as their future desires and potential, and will eventually interact with the technology.

Following the initial assessment is Stage 2, the Development or Selection of a new pathway. During this stage, information gathered in the initial assessment is used to inform the decision of which of the potential access pathways identified will be the most suitable for the individual to use. The pathway is chosen based on consensus from the caregivers, clinicians and the engineer (researcher). Where suitable switches for this pathway already exist, these are presented to the individual and caregivers for their approval before moving forward. Where no suitable technology is available, an idea for an appropriate switch is presented to the caregivers, individual and clinicians for their approval. Once the idea is approved, the engineer moves forward to develop the switch, which may involve multiple data collection sessions with the individual. The final selected or developed switch is delivered to the individual as soon as it is approved and complete. Basic training on how to set up and use the switch is provided to users and caregivers over 1 to 3 visits at the time of delivery, dependent on the number of people to be trained and their needs. Additionally, for each of the evaluation stages, the user is visited 3 times over a 2-week period and data is pooled for calculations.
Figure 2.2: Outline of the Access Technology Delivery Protocol
2.4.2 Evaluation Procedures

One of the criticisms of many assistive technology selection tools and practices is a lack of outcome data [5]. To evaluate the selected/developed access technology, we have assembled a collection of qualitative and quantitative measures to assess each of the four factors influencing response efficiency, as well as appropriateness and outcomes. The evaluations described below are administered for both the current and novel means of access, to allow for comparison.

Response Effort

A Borg Scale, taken from "ISO 9241-9 Requirements for non-keyboard input devices", is used to assess the perceived effort required to use the access pathway for both the user and the caregiver [17]. No information was available regarding the psychometric properties of the scale, however it was chosen because it has been adapted into the ISO standard. The version of the Borg Scale described in ISO 9241-9 has 12 points, ranging from zero to ten, representing the percentage of maximum muscular strength that a given effort or activity requires. A representation of the scale is shown in Figure 3.3, with descriptors in brackets representing whole-body effort. As the scale descriptors are very general, we use the scale in unmodified form to assess perceived cognitive effort required for a given task or activity. In circumstances where the user is unable to rate his or her own effort, due to cognitive difficulty for example, a caregiver is asked to give their best estimate of the user’s effort. Respondents rank their effort at each stage without being shown their previous rankings.

For users who are already working with a switch, but are seeking a new technology, a second more objective measure of response effort is deployed. The user is asked to play a game where they are required to activate their switch as many times as possible in a 30 second period. They are then be given a one-minute break, and asked to perform the same task again. The game screen shows a bright balloon that enlarges with every switch
<table>
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<tr>
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<th>Effort Representation</th>
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<tr>
<td>10</td>
<td>Very, very strong (almost max.)</td>
</tr>
<tr>
<td>9</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Very strong</td>
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<tr>
<td>6</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Strong (heavy)</td>
</tr>
<tr>
<td>4</td>
<td>Somewhat strong</td>
</tr>
<tr>
<td>3</td>
<td>Moderate</td>
</tr>
<tr>
<td>2</td>
<td>Weak (light)</td>
</tr>
<tr>
<td>1</td>
<td>Very weak</td>
</tr>
<tr>
<td>0.5</td>
<td>Very, very weak (just noticeable)</td>
</tr>
<tr>
<td>0</td>
<td>Nothing at all</td>
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Figure 2.3: ISO 9241-9 version of Borg Scale [17]
activation. The total number of activations for each trial is recorded. It is assumed that a switch that requires greater effort to activate will result in fewer activations.

Rate and Immediacy of Reinforcement

Rate and immediacy of reinforcement are recorded based on observation of the user using the access pathway as well as feedback from users and/or caregivers.

Quality of Reinforcement

Questions related to quality of reinforcement are answered through direct observation and interviews with the caregiver and/or user.

- Is the switch activation feedback clear and discernable by the participant?
- How clearly can the desires of the user be interpreted by the caregiver?
- Can the access pathway be used in a variety of different contexts, and interfaced with a variety of programs? If not, how is it limited?

Appropriateness

Since achieving a good contextual fit is essential to successful technology adoption, it is important to determine whether or not a response efficient switch is also appropriate for the user. ISO 9241-9 defines an appropriate device as one that is effective, efficient and satisfactory for the tasks being performed and the intended work environment [17]. Thus, in addition to response efficiency, efficacy and satisfaction are also measured for each access pathway.

Switch efficacy is measured using a game that is of interest to the user. The sensitivity and specificity of the switch are calculated based on manually recorded data during the game. Criteria for the game are as follows: must require low cognitive effort, must
have clear correct and incorrect responses, must have clear feedback and must have an adjustable pace.

Satisfaction is measured using the Quebec User Evaluation of Satisfaction with Assistive Technology 2.0 (QUEST 2.0) (Appendix D), available from the Institute for Matching Person & Technology Inc. [12]. The psychometric properties of the QUEST 2.0 have been verified and it can be used for both adults and adolescents [9]. The QUEST is a questionnaire that can be self-administered or interview-based and requires respondents to rate their satisfaction with each of 12 variables on a five point scale, with respect to their AT, and then list the 3 variables that are most important to them [39]. The measured variables relate to the environment, the user and the AT [39].

2.4.3 Outcome Measures

Outcomes are defined as the results of a particular intervention and outcome measures are used to demonstrate the extent to which particular goals established for an individual have been achieved [36]. Three outcomes are measured in this protocol. The first, access technology usage, is captured using automated data loggers that record each time the switch is activated. The second outcome measure is Goal Attainment Scaling (GAS). The GAS is an individualized, client-centred (or clinician-centred) outcome measure designed to capture and measure the goals of an intervention from a client or clinician perspective [41]. This internationally recognized tool helps children and families set realistic goals and focus their attention on a target [41, 34]. The use of GAS, its psychometric qualities and clinical utility in paediatrics are well documented [41, 8, 25, 24]. The GAS allows individuals with separate and unique goals to be compared in terms of their success in achieving them [8]. This is a particularly important feature when working with individuals with multiple disabilities as the intervention, and thus the goals, for each individual are based on their specific needs and levels of ability and are therefore unique. The GAS is also more sensitive to change than norm-referenced measures [25]. This
study makes use of a modified version of the typical GAS scale (Appendix B), ranging from -3 to +3, to address the issue of possible floor and ceiling effects criticized in the literature and to further improve the sensitivity of the scale [41, 8, 25]. Additionally, several studies have recommended that individuals administering the GAS have specific training on this method in order to minimize the likelihood of setting goals that are too easily achieved or having a scale in which the increments do not represent equal levels of difficulty [41, 8, 24, 25]. For this study, goals and achievement levels are establish by a SLP or OT trained in GAS, in collaboration with the family.

The third outcome is participation, which was chosen in an effort to capture the broader impact an access technology may have. The Assessment of Life Habits (LIFE-H Short Form) survey (Appendix C) is employed to evaluate this outcome. The LIFE-H questionnaire is designed to provide information about the accomplishment of common activities and social roles for individuals with disabilities, within their socio-cultural environment and according to their personal characteristics [1]. Respondents are asked to identify the degree of difficulty with which each habit is typically accomplished, the type of assistance used to accomplish the habit, and the degree of satisfaction with that level of accomplishment [13]. For children, the questionnaire is typically completed by the primary caregiver [13]. The psychometric properties of the LIFE-H have been verified for both the child and adult versions [33, 32].

2.4.4 Final Interview

There may be information that is important to the caregivers or the user that is not captured by any of the measures outlined above. To account for this, we conduct an informal interview with these individuals during the final visit. They are asked to comment upon: their intentions about continuing to use the switch (if not, why?), their subjective perception of the fit between the access technology and individual context, any problems encountered with the switch and if and how they were resolved, the perceived value of
the assessment/selection/follow-up process, and are any other thoughts or concerns they
would like to share. This final interview is intended to highlight any flaws or strengths in
the process that may have been missed by the other measures and thereby inform future
improvements to the methodology.

2.5 Case Study Example

We recruited a participant with no reliable means of access to communication, computers
or control devices to demonstrate the proposed assessment, selection/development and
evaluation protocol. It is important to note that the participant missed a lot of school
due to illness during the period of this study. To compensate for this, the follow-up
period was tracked according to the number of weeks that he was in school, and thus
able to use and train with his switch. As such, the eight and 16-week periods were not
necessarily consecutive weeks, depending on his health and attendance during that time.

2.5.1 Participant Description

The participant, here after referred to as Adam, is a 12-year old boy diagnosed with
degenerative hypotonia of unknown cause, and developmental delay. He is an only child
living at home with his mother and father and attending school as a grade 6 student in
a community classroom. He has a nurse to aid with his care during the day until 18:00,
both at home and at school.

Adam is tube-fed, has a tracheotomy and has very little movement, either voluntary
or involuntary. He experiences frequent, long-lasting seizures commonly triggered by
hot weather and fatigue. He is contingently aware, and both his hearing and vision are
normal according to his mother, as of his most recent sensory testing. Adam’s mouth is
generally ajar, unless swallowing, and he spends the majority of his time in an upright
seated position in his manual wheelchair.
During the first meeting it was determined that Adam had used mechanical button switches in the past, which he operated with both head and finger movements. However, due to the degenerative nature of his condition, he was no longer able to generate the movements required to activate those switches. In fact, at the time of this study, Adam’s only reliable movements were eye-gaze and facial expressions, particularly smiling. He was adept at using both movements for low-tech, partner-assisted communication.

2.5.2 Initial Assessment

Adam’s initial assessment took place near the end of the school year and was attended by himself, his mother, his occupational therapist (OT) and one of his regular nurses. His teacher was also consulted at a later date for her opinions on how the technology would be used. The Client Information questionnaire was completed by Adam’s mother, with input from the OT.

Several desired uses for the switch were outlined by Adam’s caregivers. These included independently accessing a computer for tasks such as reading or games as well as communicating with simple devices like a Step-by-Step [2] with the potential to graduate later to augmentative and alternative communication (AAC) software. Lastly, the switch was to be used for participating in class, which, in addition to communication, could involve controlling electronic devices in music and cooking activities. Control of electronic devices is achieved for other switch users in the classroom using a PowerLink control unit [2]. Additionally, the switch needed to be useable both at home and at school.

It was established during these initial visits that Adam’s only reliable movements were eye-gaze and facial expression. Because he was already using eye-gaze and his smile for partner assisted communication, it was assumed that using one of these movements as an access pathway would require the least amount of cognitive and physical effort.

While there are several eye-tracking systems currently on the market, the OT was concerned that Adam would be unable to use these technologies due to the narrow shape
of his eyes and his tendency to keep them half-closed. Additionally, these systems are primarily designed for use with AAC software or computer activities, and often require special adaptations for Adam’s other desired uses (e.g., DynaVox EyeMax). As a result, we decided to focus on the smile as the chosen access pathway. Adam’s OT also made plans to have Adam demo the EyeMax system from DynaVox, as a potential alternative, but it would be several months before this demo could occur.

### 2.5.3 Technology Development

At the time of this study, there were no known smile recognition access technologies on the market. Therefore, a smile switch was developed specifically to meet Adam’s needs. Through discussions with the OT, it was decided that a video based system would be used to capture and transduce the smile into an electrical signal. Solely for the purpose of algorithm development, videos of Adam were recorded using a SONY 1.0 Megapixel HandyCam MPEG-2 while he smiled in response to various yes/no questions. Previous publications report the successful isolation of specific facial features using both video and thermal imaging [20, 26, 31]. The algorithm developed for the smile switch makes use of these strategies to conduct a frame-by-frame analysis of the image to identify the area most likely to be the face, and from there isolate the region with the greatest probability of being the mouth. Isolation of the face was achieved using colour detection, while mouth detection was based on edge contrast. A change in the morphological features of the mouth area was then used to detect a smile, and an output signal was sent to a DLP-IOR4 4-channel latching relay module to activate an external device connected to the switch. The overall program is outlined in Figure 2.4. Each processing block is detailed below.

A Logitech Quickcam Pro 9000 was chosen for video capture as it is small, portable, provided high resolution (960x720 pixels) video and is adaptable to different lighting conditions. The camera was mounted on a Slim Armstrong mounting arm and attached
to Adam’s wheelchair so that his chair could be on the left hand side, approximately 25 degrees from the front of the face, to minimize the obstruction of Adam’s view. The camera was adjusted so that Adam’s face filled a rectangular box superimposed on the output video. This ensured that the view of the camera, and thus the position of the mouth, was consistent with each use, and that only a specific area of the full frame required analysis.

The image analysis program was written using MATLAB SimuLink. As suggested in the literature [20, 31], the input video was first converted to the Hue-Saturation-Value (HSV) colour space to facilitate face detection. The video was subsequently cropped down to a 400 x 400 frame around the face. The range of hues representing the colour red (0-0.12 & 0.88-1) was manually defined, as was a saturation limit corresponding to the amount of red present in the facial skin tone. This threshold is unique to each individual and was set at 0.6 for Adam. The program identified areas in the image as skin if they fell within the defined range for hue, and were less than or equal to the saturation limit. The face was taken as the largest area that met these constraints, and was isolated using blob analysis. The region of interest (ROI) was then defined as the bounding box that surrounded the area of the face, which was constrained to the 400 x 400 frame.

Once the face was detected, the mouth had to be identified. The region of interest (ROI) was filtered using the Sobel Edge Detector. Contrast values for the function were input from the graphical user interface (GUI), where the caregiver selected among three sets of lighting conditions that corresponded to different contrast values. The corresponding contrast values varied with the user’s skin tone, and for Adam were set
at 20000, 22000 and 24000. The horizontal gradient of the edge detection was used to identify the strongest horizontal edges in the ROI and a grayscale image was output with the identified edges highlighted. A contrast function was then used to enhance the image, creating a black and white frame with only the major edges highlighted. Finally, morphological operations were used to smooth out the image, as presented in Memarian et. al., and the largest protruding surface was detected using blob analysis [26]. Areas of the ROI unlikely to contain the mouth (the upper half of the face and corners of the frame) were effectively masked out.

The last portion of the algorithm was designed to detect whether or not Adam is smiling. The area identified as the mouth is now defined by a bounding box when Adam’s mouth is in a relaxed position. The bounding box will exist as long as the area identified as the mouth meets set criteria for centroid position, area and width to height ratio. When these conditions are not met, it is presumed that the shape of the mouth has changed, and the bounding box will not be created. When no bounding box exists, the user is assumed to be smiling and the program passes a 1 or high signal to a switch activation block. The switch activation block sends an output signal to activate the switch only when the program identifies a smile for a set number of consecutive frames (specified by the user in the GUI). Additionally, feedback mechanisms were incorporated such that if the switch has been activated, the program must identify the mouth as being in the relaxed position for at least 8 frames before the switch can be activated a second time. These features were included to minimize the possibility of false positives. Lastly, whenever the switch is activated, a signal is also sent to a logging function, which records the date and time of the activation. This facilitates tracking usage over the period of the study.
2.5.4 Results

Existing Access Method

At the beginning of the study, Adam did not have an access technology and was using low-tech partner assisted methods for communication. Specifically, following a yes/no question, he would be presented with a green "YES" card on the right and red "NO" card on the left, and asked to look at the card with his desired response. Occasionally, he would be presented with 4 options on a board and would be asked to choose the desired response via eye gaze. This was done primarily for learning activities in the classroom. For nearly all other classroom activities he could only participate by proxy. For example, Adam’s teacher or EA would hold his hand on the mixer during cooking activities and press the start and stop buttons for him. This was his baseline access method against which the new access technology was compared.

Response Efficiency

Results for the Borg Scale measure of response effort are presented in Figure 2.5. Adam’s teacher answered on his behalf for this measure since the 12-point scale exceeded the maximum four options from which he could independently choose. For Adam, his teacher felt that his old means of access required slightly more cognitive effort than the new switch (“Somewhat Strong” v.s. ”Moderate” respectively). Initially, the amount of physical effort required for Adam to use the new switch was estimated to be the same as for his previous means of access. However, at the 16-week follow-up period the amount of physical effort required had increased slightly from ”Moderate” to ”Somewhat Strong”. This may be a result of his most recent illness, which occurred just prior to the 16-week follow-up, and changes in his seizure medication that left him with less energy during the day. As seen in the figure, the teacher’s perception of the communication partner’s effort remained constant at ”Moderate” between the previous and the new access methods.
Figure 2.5: Borg Scale ratings for Response Effort over time
At the initial evaluation, questions regarding quality, immediacy and rate of reinforcement were focused on Adam’s low-tech communication. With respect to quality, although Adam’s mother found it relatively easy to understand his efforts to communicate, his teacher noted that it was sometimes difficult to see his eyes and thus know which sign (yes or no) he was looking at. Some of his glances were also very brief and thus deciphering their communicative intent was challenging. If Adam could not be understood, this would be communicated to him and he would be asked to answer again, but in other circumstances, caregivers resorted to their best guess of his answer. His teacher estimated that it would take between 30 and 50 seconds for her to ask a yes/no question and receive and understand his answer. For multiple-choice questions, the time frame was longer. Because caregivers were not always certain about their interpretation of Adam’s answers, it was deemed unlikely that he was receiving the desired response with every communication effort. Thus, the rate of reinforcement was likely low to moderate at best.

At the 8-week period, Adam’s teacher reported that they were able to use the switch in a variety of different settings and with different interfaces. The audio feedback from the switch was very clear and she felt that Adam understood when it did or did not activate. It was also apparent when Adam was trying to use the switch and what he was trying to do with it. At the 16-week period this pattern continued with the switch being used with an even greater number of interfaces including a computer for books and games, a Power Link connected to a fan, a foot bath, a bubble machine or a mixer, and a Step-by-Step communication device. Again, feedback for the user was clear, as were his intentions while using the switch. This versatility and clarity marked an improvement in response quality over his previous access pathway.

Adam required approximately 7 seconds (as estimated by his teacher) to activate the switch at the 8-week period and between 5 and 10 seconds at the 16-week period, depending on how he was feeling on a given day. This included a delay time between
when Adam would smile and when the switch would recognize it. This delay time lasted between 1 and 4 seconds. Once the switch had been activated, an immediate response was received from the software or other interface hardware with which Adam was working. It was reported that the switch was not always consistent from one day to the next; on some days, Adam had to try two or three times before the switch activated correctly, generating the desired response. These observations suggest an improvement in response immediacy over Adam’s previous access pathway, but a probable decrease in the rate of response.

Overall, the new access technology was at least as response efficient as the previous means of access, and offered better response quality for the targeted tasks.

**Appropriateness**

Results for measures of efficacy and satisfaction are presented in Figures 2.6 and 2.7, respectively. Data for the sensitivity and specificity measures were obtained over a 2-week period during 3 sessions at the beginning of each of the 8 and 16-week stages. The data for all 3 sessions were pooled and calculations were based on the total counts. During each session, Adam was asked to play one of two games, either ”Splat the Clown” or ”Coconut Shy”, both available on helpkidzlearn.com [3]. Both games met our criteria for interest to the user, low cognitive effort, clearly distinguishable correct and incorrect responses, clear feedback and adjustable pace. In both games, an object would appear on the screen for a set period of time (for Adam, we set that time to 10 seconds for the coconuts and ”slow” for the clowns) during which Adam was required to hit his switch to throw the object at either a clown or a coconut. The user needed five hits at the correct time in order to win the game. In each session, Adam was asked to play the game 3 times during which false positives, false negatives, true positives and true negatives were recorded. At the 8-week period, switch sensitivity measured 0.71 and specificity 0.76 based on the formulas below. At the 16-week period, sensitivity was calculated to
Figure 2.6: Sensitivity and Specificity results over time

be 0.78 and specificity 0.64.

\[ Sensitivity = \frac{TruePositives}{TruePositives + FalseNegatives} \]

\[ Specificity = \frac{TrueNegatives}{TrueNegatives + FalsePositives} \]

The QUEST 2.0 survey was completed by Adam’s teacher at both the 8-week and 16-week follow-up points. At 8-weeks, her satisfaction rated at 3.4 overall and increased to 4.5 out of 5 at 16-weeks. The lowest scoring category at both follow-up times was 'Effectiveness', with a score of 2 out of 5. The three categories identified as most important were all device-related dimensions, namely, 'Easy to Use', 'Adjustments' and 'Effectiveness'.
Figure 2.7: Satisfaction ratings over time
Outcomes

Usage  Adam used his switch on a total of 22 days during the first 8-week period, usually once a day for 1 hour at a time. This averaged to between 2 and 3 times per week. During the second 8-week period, Adam used his switch on 28 days, again typically once per day and for 0.5 to 1 hour. This averaged to usage between 3 and 4 times per week. At the end of the study, Adam was still using his switch on a regular basis.

Goal Attainment  When Adam’s new access technology was delivered, two goals were set up for him by the OT and his teacher using Goal Attainment Scaling (GAS). The goals were set keeping in mind the 16-week study time frame. The first goal was to read and listen to books independently on the computer, and the second was to use a Step-by-Step communication device. At the 8-week follow-up mark, Adam was still at the starting level (a score of -2) for his reading/listening goal, and had only progressed to the ‘Somewhat less than Expected’ level (a score of -1) with the Step-by-Step goal. However, by the 16-week follow-up, Adam had achieved both goals. In reading, he had reached the ‘Expected’ Level (score of 0), and with the Step-by-Step he scored ‘Somewhat Better than Expected’ (score of +1). An improvement of 2 points or greater over the starting value is considered clinically significant with GAS [41, 8]. Goal attainment was scored by his teacher who worked with Adam on both activities.

Participation  The LIFE-H for Children - Short Form, was administered in interview style with Adam’s teacher as the respondent before he received the new access technology and at the end of the 16-week period. Results are illustrated in Figures 2.8 and 2.9. The total weighted score at the beginning of the study was 38.1 out of a possible 120. After delivery of the new access technology and 16-weeks of training, the total weighted score had increased to 52.7. There were both increases and decreases in scores across many categories, however the three showing the most marked increases were directly
attributable to activities for which the new access technology was used. As highlighted in Figure 2.9, these were Education, Communication and Nutrition, specifically the habit of helping with meal preparation.

**Final Interview**

The final interview was conducted with Adam’s teacher. In response to our questions, she noted several difficulties with the switch itself, including the delay and the number of false positives and negatives under certain conditions, particularly if Adam’s face was flushed. However, she also remarked that they are still using the switch and plan to continue to do so. She thought that the switch was a good fit for both Adam and his
Table 2.9: LIFE-H Weighted Scores by Category

<table>
<thead>
<tr>
<th>Category</th>
<th>Initial Weighted Score</th>
<th>Final Weighted Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Nutrition</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td>5</td>
<td></td>
</tr>
</tbody>
</table>

Figure 2.9: LIFE-H Weighted Scores by Category
environment; it played well to his strengths by focusing on facial expression, could be used for all of the applications they wanted it for, and was portable, allowing them to move around the different classrooms and facilitating switch practice at home. Although our follow-up procedure was a time intensive process in terms of teacher commitment, Adam’s teacher said that she found the process beneficial.

2.6 Discussion

The results for the response efficiency measures indicate that Adam’s new means of access is more efficient than his previous means, with respect to the tasks that the switch could perform. A possible decrease in the rate of response is compensated for by improved quality and immediacy, and no change overall in the amount of effort required for both Adam and his teacher. This suggests that our assessment and development produced the intended results: an access technology that is more efficient than the user’s previous means of access.

Additionally, when combined with satisfaction and efficacy results, the assessment appears to result in a technology that is appropriate to the user, as defined by ISO 9241-9. The sensitivity and specificity scores are not ideal, at 0.78 and 0.64 respectively, and unsurprisingly the category of "Effectiveness" had the lowest score in the QUEST 2.0 satisfaction rating. This is also reflected in the lowered rate of response that Adam’s teacher commented on, as multiple attempts were often required before the switch would activate. This indicates that any efforts towards switch improvement ought to focus on improving the robustness and effectiveness. However, despite all of this, the overall satisfaction rating remained very high (4.5/5.0) and the teacher still stated in the final interview that she felt the switch was a good match for Adam. The high satisfaction result in light of modest numerical sensitivity and specificity, suggests that switch accuracy is perhaps over-emphasized as the fundamental outcome of an access technology [20,
Although Adam was unable to give his comments directly, his teacher noted that even when the switch was not activating appropriately, Adam remained motivated and persevered, in her opinion, because he was finally able to control something on his own. Overall, Adam appeared to become more frustrated by false negatives (measured by sensitivity) than false positives. As the sensitivity score was reasonably high at the final measurement stage, this may explain his continued motivation.

Impact on outcomes are what make any technology meaningful. In Adam’s case, he was using his new technology on a regular basis to participate in activities and control equipment that was previously inaccessible. As Adam had yet to receive an AAC device, the amount of time spent using the switch seemed reasonable given the activities it was being used for. He accomplished both of the goals set out for him using GAS, and even achieved greater than the expected level for his communication goal. Additionally, there was an overall improvement in his LIFE-H score, a quality of life measure focused on participation. The LIFE-H is a very broad measure and thus there are many factors that can influence this score, including health, family situations, and funding. Outside of receiving the new access technology, all of these factors were left uncontrolled. As one might expect, there were both positive and negative changes across the habits categories of the LIFE-H after the 16-week period, reflecting the many changes in Adam’s life. However, the overall score for the questionnaire did increase after the new access technology was implemented. Furthermore, the 3 categories that showed the most marked increases in weighted score can be directly connected with activities that Adam is now able to accomplish using his switch. This demonstrates that access to an appropriate switch alone can have a positive impact on the life of the user, and corroborates previous evidence of positive impact of access technologies (e.g. Blain 2010 [6]). By association, an assessment procedure that results in the delivery of an appropriate access technology can directly lead to this positive impact.

A major advantage of the new Access Technology Delivery Protocol is its flexibility.
The inclusion of the multi-disciplinary team, including caregivers and the user, allows the interview process to work; a lengthy reassessment of function and abilities is not necessary because those who are most informed are present to provide the information. Second, in focusing the interview on the user’s needs and abilities, as opposed to the technology, the protocol renders any controlled movement or physiological process an admissible access pathway. In many cases, clinicians and others first look at what types of technology are available, then try to fit the user into one of those categories. By focusing on the user’s abilities from the start, we can turn the emphasis to choosing, creating or modifying a technology to fit them as individuals. In Adam’s case, his smile was his best-controlled movement and he had access to a technology design team. Therefore, although no smile-based technologies existed on the market, a new switch was developed that made use of this ability.

2.7 Conclusion

This chapter presented a novel, response efficiency-motivated protocol (the Access Technology Delivery Protocol) for the provision of access technologies and demonstrated the procedure via a case study. The protocol featured a multi-stake holder initial assessment, access technology development/selection and a two-stage evaluation procedure. Although the case results were positive, the procedure ought to be tested with many more individuals with severe and multiple disabilities given the diversity of this population. This will be addressed in Chapter 3.
Chapter 3

Access Solutions for Children with Cerebral Palsy

This chapter describes the application of the ATDP with two children diagnosed with cerebral palsy. Sections 3.1.1 and 3.1.2 may be skipped as the information has already been presented in sections 2.2.2 and 2.2.3. Goals set for the children may be found in Appendix blah.

3.1 Introduction

Assistive technology (AT) can be defined as any item, piece of equipment or system that is used to increase, maintain or improve the functional capabilities of individuals with disabilities [36]. These devices have the potential to greatly enhance the lives of users by increasing the level of autonomy with which individuals with disabilities participate in daily activities [39]. However, nearly 30% of assistive technologies are still abandoned within the first few months of use [15, 36]. It has been proposed that the probability of AT abandonment could be diminished by the application of the concept of response efficiency to the development and implementation of assistive technology [18].

In a previous chapter, we introduced a response efficiency-theoretic protocol for the
provision of access technologies to individuals with multiple and severe disabilities [29]. We demonstrated the application of the protocol with a 12-year old boy with degenerative hypotonia and developmental delay. The purpose of the present study was to further delineate the merits and limitations of this protocol through its application to two severely disabled children seeking access technologies. The demographic, medical and educational background of each individual differed greatly from those of the child with whom the protocol was originally proposed, as well as from each other. As such, we intended to explore the robustness of the protocol.

3.1.1 Access Technologies

The form of assistive technology used to translate the intentions of a user with severe physical impairments into functional interactions is known as an access technology, or more commonly a switch [40]. An access technology consists of two components, an access pathway and a signal processing unit, and represents only one element of a full access solution (Figure 3.1) [40]. When paired with an appropriate user interface, access technologies can activate anything from computers to lights and power wheelchairs [40]. The sensors or input devices through which an expression of functional intent is transduced into an electrical signal make up the access pathway [40]. The signal processing unit drives the user interface by analyzing the input signal from the pathway and generating a corresponding control signal [40]. An access technology that is well-suited to the individual is essential to the success of all components of an access solution.

3.1.2 Response Efficiency

Response efficiency theory states that when individuals have the opportunity to choose between two or more functionally equivalent alternatives, they will select the option that they perceive as most efficient [18]. There are four factors that influence an individual’s concept of efficiency [18]:
Figure 3.1: Components of an access solution within the user’s environment

1. Rate of reinforcement - The rate at which the individual receives a response, e.g. every time they use the technology, every other time, every third time etc.

2. Quality of reinforcement - How closely the reinforcement coincides with the user’s expectations e.g. exact match, close match, or complete mismatch.

3. Response effort - The physical and cognitive effort required.

4. Immediacy of reinforcement - The delay, if any, between using the technology and observing the desired result.

Each factor contributes to the overall perception of efficiency, however the weighting of each factor’s influence can vary from individual to individual, and within individuals, depending on the device or the environment [22, 30].

3.2 Methods

The Access Technology Delivery Protocol is outlined in Figure 3.2. For a detailed description of the protocol, please refer to the previous chapter [29]. The initial assessment
is conducted primarily through an interview process, with additional information being collected through a Client Information Questionnaire (modified from [28, 27]). The focus of the interview is on gathering as much information as possible about the user and caregivers, and what they would perceive as a response efficient solution. From Stage 3 through to the end of the follow-up process, the new and previous access methods are evaluated in terms of: (1) response efficiency using the ISO 9241-9 Borg Scale [17], Balloon Game, observation and interview; (2) appropriateness using sensitivity and specificity (estimated from game play) the QUEST 2.0 [39], and (3) personal and social impact via a usage log, the Modified Goal Attainment Scaling (GAS) [41] and LIFE-H for Children - Short form [1].

The arsenal of measures was incorporated into the protocol in an effort to broadly capture the usability and impact of the access technology. A final interview is conducted at the end of the follow-up period in an attempt to capture any pertinent information that was missed by the other measures.

3.2.1 Description of the Participants

Jessica

The first participant, referred to as Jessica, was a 12-year old girl diagnosed with Cerebral Palsy (CP). She was non-ambulatory and had spasticity in her upper body and limbs. She had also been diagnosed with a hypersensitive startle reflex. She lived at home with her mother, father, brothers and sisters, and attended a specialized primary school for children with physical and developmental disabilities.

Jessica spent the majority of her time in a seated position in her manual wheelchair. She had limited control of her trunk and neck, and partial control of her arms and hands. She was contingently aware and competently followed cues. She had a visual impairment, the severity of which was unknown, but her hearing appeared to be intact.
Figure 3.2: Outline of the Access Technology Delivery Protocol
Jessica experienced fatigue late in the day as well as greater tightness in her limbs and increased thirst.

At the time of study enrolment, Jessica had never used a mechanical switch or other form of access technology. She produced vocalizations, similar to a ”ya” sound, to indicate a ”yes” response, and touched her right shoulder to indicate a ”no”. She also has a sign for ”thirsty”, which involved bringing her hand to her open mouth. She had a communication book that could be used with a partner to convey other commonly used messages, such as ”I want to talk about my day”. She was easily understood by most of the people with whom she communicated. Jessica did not use a computer in the classroom or at home.

**Peter**

Peter was a 14-year old boy also diagnosed with CP and developmental delay. He lived at home with his parents and sisters and attended public school in a community classroom. Peter was quadriplegic with no movement in his lower limbs and spasticity in his upper body and limbs. He was tube-fed and experienced frequent seizures. He was contingently aware, and both his vision and hearing were thought to be normal. Peter spent the majority of his time seated in his manual wheelchair. His posture varied between upright and slumped forward while seated. He had reliable control of his head and eye movements.

Peter was currently using a mechanical button switch, which he activated by turning his head slightly to the right. He used this switch both at home and at school with a DynaVox Vmax communication system, a Step-by-Step communication device and various classroom computer programs. He also used eye gaze to make choices between 2 or more options.
3.2.2 Assessment

Jessica

Jessica’s initial assessment took place at her school 5 months into the school year. It was attended by herself, a researcher, an Educational Assistant (EA), and two of the school’s therapists (Occupational Therapist (OT) and Speech Language Pathologist (SLP)). Jessica’s teacher also provided some information regarding Jessica’s interests and classroom activities. The Client Information questionnaire was completed by the SLP.

The desired uses outlined for Jessica’s switch included accessing computer games and online stories, communicating with a Big Mac, Step-by-Step and eventually a DynaVox Vmax communication system that had recently been prescribed, and control of electronic devices (kitchen appliances, tape recorders etc.) that would allow her to participate in classroom activities. The school used adapted computer mice and a PowerLink control unit for facilitating switch access for students. For the period of the study, Jessica only used her switch in a school setting. However, the school team foresaw that she would wish to use it at home in the future and asked that the home environment be taken into consideration.

Jessica had been assessed for 2-button switch access just prior to this study, but the assessment and school teams found that, due to limitations in her upper limb control, it was difficult to position the buttons in such a way that she could reliably depress both. As a result, the research team, in collaboration with the clinicians, decided to focus on a technology that made use of her other means of access, i.e., vocalization, with the intention of combining the vocal solution with a single button switch to facilitate dual switch access. Because Jessica was already successfully using vocalizations for yes/no communication, it was assumed that a technology that made use of these capabilities would be easy for her to both learn and use.
Peter

Peter’s initial assessment took place in the second last month of the school year and was attended by himself, a researcher, his OT and SLP, and his parents. The Client Information Questionnaire was complete by interview with his mother and OT.

The desired uses for Peter’s switch mirrored the activities targeted with his existing switch (communication, computer etc.). As such, the switch would have to be compatible with his current DynaVox Vmax system, as well as the Step-by-Step and computer interfaces. The switch needed to be useable both at home and at school.

Peter’s known reliable movements included eye gaze and head movements. He had previously been assessed for an eye gaze access technology, but did not meet the requirements for approval for that technology. As such, the research team focused on his head movement. Although both Peter’s parents and clinicians felt that he was reasonably successful with his current mechanical switch, Peter’s frequent spasms often resulted in his head slamming into the mounting arm and there was concern that this could lead to serious injury. Additionally, Peter tended to slump forward in his chair when fatigued or disinterested. His caregivers expressed a desire for him to have a switch that would still be accessible and useable when in this position, so that he could still participate in activities or conversations when tired. Finally, because Peter was already trained to turn his head to activate his switch, his family asked that the new technology make use of this same motion so that he would not have to retrain. His OT also asked that a feature be included so that he could use a turn in the opposite direction as a second activation in the future.
3.2.3 Access Technology

Jessica

The switch chosen for Jessica was a vocal cord vibration (VCV) device that was developed by Falk et. al. [11]. This particular switch offered several advantages over other vocalization detection technologies on the market: immunity to environmental noise, detection of nonverbal vocalizations, detection of both quiet and loud sounds and filtration of coughs and respiratory noises [11]. The switch consists of a small dual-axis accelerometer placed on the surface of the neck anterior to the cricoid cartilage where it picks up vibrations as air passes across the vocal cords [7]. The signal processing unit sends a message to activate the switch only if the vibrations are periodic in nature. Periodicity is characteristic of voiced vocalizations, including all vowel sounds and some consonants, as well as hums and grunts. Coughs and other non-speech sounds do not produce periodic vibrations.

Peter

For Peter, the researchers set out to develop a non-contact version of his current mechanical switch to minimize the potential for injury during his spasms. Many types of non-contact proximity switches, such as those available from Adaptive Switch Labs Inc. [16], are currently available on the market. However, these switches still require some form of mounting and thus the potential for injury persists. As a result, they were excluded from further consideration.

The newly developed switch deployed a dual-axis gyroscope (part number 497-10363-ND from Digikey) from ST Microelectronics to acquire signals related to the rate of angular rotation. The gyroscope was attached to a headband worn by the user such that the sensor was positioned anterior to the upper right temple. The pitch and roll axes were oriented to detect the angular rates of rotation about the anatomical superior-inferior
axis and the medial-lateral axis. When using the switch, a baseline signal was recorded at the beginning of each session to determine the relative centre position of the head. Subsequently, a turn of the head to the right induced a positive deflection in the pitch signal. If the change exceeded an empirically set threshold, the switch produced a single activation. The user’s head had to return to the centre position before the switch could be reactivated. A reset button was included on the device to allow the caregivers to redefine the centre position at any time.

There were two additional options for the user/caregivers. The first made use of the roll signal to determine if Peter was sitting upright or slumped forward. An on/off toggle was included on the switch interface, allowing a caregiver to decide whether or not Peter ought to be able to continue using his switch in the slumped position. The second option was an on/off toggle that, when in the ”on” position, allowed Peter to use a left turn of his head as a second activation mode.

3.3 Results

3.3.1 Response Efficiency

Response Effort

A Borg Scale (Figure 3.3), taken from 'ISO 9241-9 Requirements for non-keyboard input devices' was used to assess the perceived cognitive and physical efforts required to use the access method. Results for the Borg Scale measure of Response Effort are presented in Figure 3.4 and Figure 3.5. Jessica’s SLP, a frequent communication partner, answered on her behalf for the evaluation of her current means of access. Unfortunately, the SLP did not have much interaction with the new access technology. Therefore, the OT was asked to respond for the 8-week and 16-week follow-up evaluations. Peter’s mother responded on his behalf as comprehending the scale was deemed to be beyond his cognitive abilities
Chapter 3. Access Solutions for Children with Cerebral Palsy

<table>
<thead>
<tr>
<th>Points</th>
<th>Effort Representation</th>
</tr>
</thead>
<tbody>
<tr>
<td>10</td>
<td>Very, very strong (almost max.)</td>
</tr>
<tr>
<td>9</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Very strong</td>
</tr>
<tr>
<td>6</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Strong (heavy)</td>
</tr>
<tr>
<td>4</td>
<td>Somewhat strong</td>
</tr>
<tr>
<td>3</td>
<td>Moderate</td>
</tr>
<tr>
<td>2</td>
<td>Weak (light)</td>
</tr>
<tr>
<td>1</td>
<td>Very weak</td>
</tr>
<tr>
<td>0.5</td>
<td>Very, very weak (just noticeable)</td>
</tr>
<tr>
<td>0</td>
<td>Nothing at all</td>
</tr>
</tbody>
</table>

Figure 3.3: ISO 9241-9 version of Borg Scale [17]

at the time. For this particular measure, Peter was assessed at 12-weeks instead of 8 due to his mother’s lack of availability at the 8-week period.

As seen in Figure 3.4, the estimated physical effort required for Jessica remained constant throughout the process. This was expected as she used vocalizations for access both with and without the new technology. There was an increase, from 0.5 (Very, very weak) to 3 (Moderate), in the estimated cognitive effort required for Jessica to use the VCV switch as compared to her previous means of access. This is most likely attributable to the fact that she had no previous experience using switches. For the caregivers, there
was a slight increase in the amount of physical effort required at the 16-week period. However, the amount of cognitive effort decreased significantly, from 7 down to 3, with the new access technology.

Despite a slight increase in required effort at the 12-week period (from 4 to 5), the estimated effort required for Peter to use the new access technology decreased in both the physical and cognitive domains at the 16-week follow-up, as compared to his mechanical button switch (Figure 3.5). The original increase may be attributable to his learning to use the new switch. For Peter’s mother, the required cognitive effort for the new switch at the 16-week follow-up was slightly higher than that of previous pathway. In terms of physical effort, the final result was a decrease, from 2 to 0, largely attributable to the difficulties in mounting the previous mechanical switch. The spike in the physical effort rating at the 12-week follow-up period may have been due to the incessant technical difficulties with the Vmax system that surfaced at that time but were later resolved.

Because Peter already had use of an access technology at the beginning of this study, we were able to implement our secondary measure of response effort, the balloon game, with him. The balloon game is a custom program that shows a picture of a bright yellow balloon on the screen. When the player activates his or her switch, the balloon increases in size. Peter played the balloon game twice in each session (3 sessions per measurement period), for 30 seconds each time, and with a 1 minute break between games. He was asked to activate his switch as many times as possible during the 30 second period and the number of activations was recorded at the end of each game. It was assumed that a switch that requires greater effort to activate will result in fewer consecutive activations.

Peter’s results for the balloon game are shown in Figure 3.6. The minimum, maximum and average numbers of activations with his new switch were all lower than what he accomplished with his previous mechanical button, suggesting that the new switch required more overall effort to activate. This increased effort may partially be attributable to a change in his seizure medication just prior to the 8-week follow-up point. The new med-
Figure 3.4: Borg Scale results for Response Effort over time for Jessica
Figure 3.5: Borg Scale results for Response Effort over time for Peter
Old Switch 8-week New Switch 16-week

![Graph of Balloon Game score over time for Peter](image)

Figure 3.6: Balloon Game score over time for Peter

...drowsiness throughout the day and noticeably impacted the speed of his head movements.

**Quality, Immediacy and Rate of Reinforcement**

At the initiation of this study, Jessica was not using any form of access technology. Therefore questions pertaining to quality, rate and immediacy of reinforcement all focused on her low tech means of communication. In terms of quality, Jessica’s SLP indicated that her yes/no responses were very clear and immediate. However, with this binary scheme, it could take several minutes for her to select among several different options. Further, for communication beyond a simple yes and no, it was difficult to decipher...
what she wanted to say. When using her communication book, she was restricted by
the limited vocabulary within, and caregivers could only derive a general sense of her
communicative intent based on her body language. Due to her lack of motor control,
Jessica was unable to directly participate in some classroom activities, such as music and
cooking. As a result of the ambiguity in her low tech communication, it is unlikely that
Jessica was obtaining the response she desired with every communication effort.

At both the 8-week and 16-week follow-up periods, Jessica’s new switch could be
used for all of the activities it was intended for, with the exception of the DynaVox
Vmax system, which did not arrive before the study was completed. Activities included
classroom cooking activities and a game called "Beauty Parlour", where the girls in
the class would use switches to control the hair dryers and dry each other’s hair after
swimming. The feedback came primarily from the interfaces to which the switch was
connected, and this feedback was clear to both the user and the caregivers. Overall,
caregivers exhibited greater certainty over what Jessica wanted to do or say with the
switch. The switch activated immediately when triggered. False negatives occurred only
when the sensor became physically displaced. Jessica was usually able to activate the
switch on the first try. These results mark an improvement in clarity, immediacy and
rate of response for the targeted switch activities.

3.3.2 Appropriateness

The "ISO 9241-9 Requirements for non-keyboard input devices" defines an appropriate
device as one that is effective, efficient and satisfactory for the tasks being performed
and the intended work environment [17]. This is the definition of appropriate used in
this study and thus, in addition to response efficiency, switch efficacy and satisfaction
are measured.
Switch Efficacy

The results for the switch efficacy evaluations are shown in Figure 3.7. For both participants, three data collection sessions were held, on separate days over a 2-week period, at both the 8-week and 16-week follow-up points. For Peter, an additional three sessions were conducted just prior to the delivery of his new switch in order to assess the efficacy of his previous mechanical button switch. Data for all three sessions within a period were pooled for sensitivity and specificity calculations. This approach was taken to limit the effects of an atypically good or bad session.

Testing for Jessica was done using a yes/no question game in order to accommodate her vision impairment. Jessica’s SLP or teacher asked her simple questions with definite correct and incorrect responses. Jessica was instructed to use her switch (i.e. produce a vocalization) to indicate a "yes" response, and to use her hand gesture, touching her right shoulder, for "no". Each session contained 50 questions, and results for true positives, true negatives, false positives and false negatives were manually recorded. During each session, Jessica’s switch was connected to a computer that logged her activations.

As seen in Figure 15, Jessica’s VCV switch showed extremely high specificity ( >90%) at both the 8-week and 16-week follow-up periods. Sensitivity, however, was much lower, at only 65% and 60%. This was most likely caused by the slack in the sensor band and the ensuing suboptimal sensor placement. Jessica did not like wearing anything around her neck, and as a result, frequently requested that the strap be loosened. Furthermore, the question game was not one in which Jessica needed the switch for her response or action to be understood. Therefore, she was not concerned about the risk of reduced sensitivity due to loosening of the band.

Quantitative performance measures for Peter were estimated via the games ”Splat the Clown” and ”Coconut Shy”, both available at helpkidzlearn.com [3]. Both games were of interest to the user, demanded low cognitive effort, had distinct correct and incorrect choices, and had an adjustable pace and clear feedback. In both games, an
object appeared on the screen for a set period of time (timing set at "normal" for the clown game and 5 seconds for the coconuts) during which the user had to activate the switch to throw the object at a clown or coconut. Five correct activations were required to complete a game. Except in circumstances where Peter was unable to play (2 sessions in which he experienced a seizure part way through), each session consisted of three games. True positives, true negatives, false positives and false negatives were recorded manually during the sessions and sensitivity and specificity calculated. As seen in the graph, Peter’s new access technology outperformed his previous mechanical button switch in terms of sensitivity and specificity at both follow-up periods, reaching 81% and 83% respectively.

Peter’s original mechanical button switch could be used with all of the interfaces that the caregivers desired. The switch feedback was clear to both caregivers and Peter himself. When using the switch with his Vmax communication system, it would take Peter 1-2 minutes to communicate a message. Although his complaints were apparent when the wrong message was selected or when he was misunderstood, it would often take him several tries to convey the desired message.

At both follow-up periods, Peter’s new access technology could also be used for all of the desired activities. The switch feedback was clear, primarily due to the interfaces to which it was connected. However, the new technology required more time to activate and at times the rate of response was lower than that of his mechanical switch.

**Satisfaction**

Satisfaction ratings for Jessica’s switch were provided by her OT using the QUEST 2.0 questionnaire. The rating for the "Comfort" item of the scale was based on feedback from Jessica herself. At 8 and 16-weeks, the overall satisfaction rating was 4.0 and 3.8 out of 5, respectively. The lowest scoring item at the 8-week period was safety, which scored 2 out of 5. The OT commented that she would not consider any device that had
Figure 3.7: Sensitivity and Specificity results over time

to be worn around the neck as safe. At the 16-week period, there were three low scoring items, namely, safety, comfort and adjustments, each of which scored 2 out of 5. The change in the comfort score was based on Jessica’s feedback that she did not like wearing something around her neck. Similarly, the change in the adjustments score related to Jessica’s frequent requests for loosening the sensor band. The items identified as most important at the 8-week milestone were Comfort, Safety and Effectiveness, while at the 16-week mark, these were Comfort, Safety and Ease-of-Use.

Satisfaction ratings for Peter’s switch were provided by his mother. The overall satisfaction rating for Peter’s old mechanical button switch was 3.9 out of 5. The lowest scoring item was Safety, with a score of 2 out of 5. The response for the Adjustments
item was invalidated as both the 2 and the 3 were circled in the response. The items identified as most important were Safety, Effectiveness and Easy to Use.

At the 8-week follow-up period, the overall satisfaction was 4.5. The lowest scoring item was Adjustments with a score of 3 out of 5, and the items identified as most important were Safety, Easy to Use and Professional Service. At 16-weeks, the overall satisfaction score had risen to 4.7. The lowest scoring items were Easy to Use and Effectiveness, each with a score of 3. The three most important items were Safety, Easy to Use and Effectiveness.

Figure 3.8: Satisfaction ratings over time
3.3.3 Outcomes

Usage

Automated data loggers were used to record switch usage for both participants.

Jessica used her switch on a total of 16 days during the first 8-week period, between 20 min and 1 hour at a time. This averages to a usage frequency of 2 times per week. In the second 8-week period, Jessica used her switch on 20 different days, typically between 30 min to an hour per day. This averages to a usage frequency between 2 and 3 times per week. Her switch was only used at school, and at the end of the study she was continuing to use the switch 2 to 3 times per week.

At the beginning of the study, Peter was using his mechanical button switch both at home and at school, and his mother estimated that he was using it daily. During the first 8-week period, Peter used his new switch on a total of 12 days, usually between 0.5 and 1 hour each day. This represents a usage frequency between 1 and 2 times per week. However, 9 of the 12 usage days occurred in the final 4-weeks of the 8-week period. This was the result of delays in scheduling the switch training session with the school. During the first 4-weeks, the switch was used only at home. During the second 4-week period, when the switch was being used at school, average usage was between 2 and 3 times per week.

Results for the second 8-week period were estimated by Peter’s teacher due to a failure in the data logging equipment. Between weeks 8 and 12, Peter’s teacher estimated that his switch was being used once a week for approximately 25 minutes. Between weeks 12 and 16, the switch was not used at all. It is important to note that, in addition to the previously mentioned changes in medication, Peter’s caregivers also had many problems with his Vmax system throughout the 16-weeks of follow-up.
Goal Attainment

Two goals were set for Jessica when her new switch was delivered using the modified GAS scale. The goals were set by Jessica’s SLP, teacher and OT with the help of a consultative OT who was well-versed with GAS administration. The first goal related to Jessica doing activities that required coordination between a button switch and her VCV switch. The second goal related to her using the VCV switch in a variety of different activities. At the 8-week period, Jessica had reached the -1 level (Making Progress) for both goals. By the end of the 16-week period she had achieved the target level of 0 for both goals.

One goal was set for Peter using the modified GAS when his new switch was delivered. The goal was set by his mother and the researcher in consultation with an SLP and OT who were trained in the GAS method. His goal pertained to learning to use the switch when his body was in the slumped position. At the 8-week follow-up point, Peter had had no practice in using the switch with his head down and remained at the starting level of -2. By the 16-week follow-up period, Peter had some practice with the switch and had progressed to the -1 level but did not reach the target level of 0.

Participation

The LIFE-H for Children - Short Form was administered in interview style, with Jessica’s OT as the respondent, at the beginning of the study and again at the end of the 16-week follow-up period. The results are illustrated in Figures 3.9 and 3.10. One category, Housing, was excluded from scoring because the respondents worked with Jessica exclusively at school, and the switch was also used only in the school environment. The total weighted score at the beginning of the study was 40.1 out of a possible 110. At the end of the 16-week training period with the switch, the total weighted score had increased to 51.5. Of the eleven categories evaluated in the questionnaire, there were 4 that had the potential to be directly impacted by the availability of the new switch:
Communication, Education, Nutrition and Personal Care. Specifically, the 'taking part in meal preparation' habit in the Nutrition category and the 'attending to personal hygiene' habit (that included doing hair) in the Personal Care category were those affected by the switch. The initial and 16-week scores for each of these categories are highlighted in Figure 3.10. The Communication category only improved slightly. This is unsurprising as the Dynavox Vmax communication system (with which Jessica was to use her switch) had yet to arrive at the time of study completion. The Nutrition and Education categories exhibited the greatest levels of improvement, which may be the result of her switch-enhanced ability to participate in more classroom activities (such as cooking).

Peter’s mother completed the LIFE-H measure for him in a self-administered style at both the time of switch delivery and after the 16 weeks of follow-up. Unfortunately, the initial questionnaire was completed incorrectly, with a large number of habits being listed as "Not Applicable" when they were in fact a part of Peter’s daily living. As a result, there was no point of comparison for the 16-week scores and they were therefore excluded.

**Final Interview**

The final interview for Jessica was conducted with her OT. She indicated that the switch was still in use at the end of the study, usually 3 times per week. In terms of suitability, she felt that the switch met Jessica’s need for participating in activities, but could also impair her natural communication. Because she was using her vocalizations for both direct communication and switch activation, her verbal responses to questions and her laughter produced false activations while donning the switch. Jessica’s OT felt that the follow-up process was very beneficial. It worked as motivation for both Jessica and her caregivers and ensured continuity with the training. In general, she found the experience to be very positive.

Peter’s final interview was conducted with his mother. At the end of the study, he was
Figure 3.9: LIFE-H Total Weighted Score for Jessica
Figure 3.10: LIFE-H Weighted Score by Category for Jessica
still using the switch occasionally with her, and although the school reported differently, she believed he was still using it on a regular basis at school. She felt that the switch alleviated their concerns about safety and appreciated the flexibility of Peter being able to use it without sitting upright. She also believed that the accuracy was lower than that of his mechanical button switch, which impacted his independence. Finally, she felt that the full follow-up process was beneficial. She also commented that the home and school-based evaluations were great enablers for trying new technologies, as the family did not need to make frequent, burdensome trips to a testing centre.

3.4 Discussion

Based on the results of the evaluations, Jessica’s assessment appears to have yielded a technology that is more response efficient than her previous means of access. This is primarily due to improvements in clarity, caregiver effort and the variety of activities in which she was able to participate. Additionally, despite issues with comfort, the satisfaction rating at the end of the study remained high (3.8/5.0). The specificity score for the switch was excellent, exceeding 0.90. The sensitivity, however, was not ideal, hovering between 0.60 and 0.65 due primarily to user preference for a slack neckband. Despite this fact, ”Effectiveness” was not one of the lowest scoring items in the satisfaction questionnaire, and the OT commented in the final interview that she felt the switch was well-suited to the targeted activities, suggesting that the response efficient switch was also an appropriate fit to the user.

Although Peter’s mother estimated both Peter’s and her own effort requirements to be lower with the new switch, Peter’s balloon game results seem to contradict that assessment. Additionally, the rate and immediacy of response with the new switch were reported as lower. Combined, the evaluation results indicate that Peter’s assessment did not result in a switch that was more response efficient than his previous means of
access. One potential cause for this was the change in Peter’s medication. As previously noted the new medication left Peter very drowsy during the day and caused a noticeable slowing of his movements, including his head turn. As the new gyroscope-based switch is affected by the rate at which movements are made, these changes could have a significant impact on Peter’s switch control. The change in medication may also account for the discrepancy between the maternal assessment of effort and the balloon game results. Because Peter was tested over 3 sessions at different times of day and he seemed to find the game enjoyable, it’s unlikely that the Balloon Game results would have been negatively impacted by a lack of motivation or a single day of feeling tired or unwell. On the other hand, Peter’s mother was already well-attuned to recognizing the requisite head motion and also knew that this movement was familiar to Peter. As a consequence, she may not have perceived any extra effort arising from the changes in his medication.

Despite the clear decline in response efficiency, Peter’s new access technology actually outperformed his previous mechanical button switch in terms of sensitivity and specificity. This finding contradicts the maternal perception of decreased accuracy with the new switch. One possible explanation of this discrepancy may be the differences in tasks. For the sensitivity and specificity measures, Peter played a computer game, a focused task over a set period of time. However, his mother observed him during the day, when Peter’s switch was often connected to his Vmax communication system. With the previous switch, Peter could more easily look around the classroom, watch activities, and usually only activate when he wished to actually use the Vmax. The new switch was unable to distinguish between head turns associated with changes in eye gaze, and head turns intended to activate the switch. As such, in an unfocused task, such as being connected to the Vmax, the new switch was likely more prone to false activations than the previous switch. This may explain the difference in observational evidence versus the calculated sensitivity and specificity.

In terms of satisfaction, the new switch also outperformed the previous mechanical
button, with a rating of 4.7 versus 3.9. This was most likely due to the increase in satisfaction with the safety of the switch, identified as one of the most important factors. However, ISO 9241-9 defines an appropriate device as one that is effective, satisfactory and efficient for the user and the tasks they wish to perform [17]. As such, due to the lower efficiency, the new switch cannot be considered as an appropriate device for Peter. This is an important finding, as many studies rely solely on sensitivity and specificity measures to determine whether or not a device is suitable for a user. Clearly, these measures do not capture all of the information necessary to make that determination.

The outcome and quality of life measures were used to determine the impact of the access technology on the user’s life, which is what makes any technology meaningful. At the end of the study period, Jessica was using her new switch on a regular basis to participate in classroom and school activities that were previously inaccessible. She achieved both of the GAS goals set out for her and saw an increase in her LIFE-H score, including increases in categories that are directly attributable to the new access technology. These results provide evidence of the positive impact of an appropriately delivered access technology. By association, an assessment and follow-up protocol that results in an appropriate technology can also have a positive impact.

Conversely, Peter was no longer using his switch at school at the end of the study period and had not reached the target level for his GAS goal. In addition to his new switch being less efficient and less appropriate than the mechanical button switch, there were also several other factors at play. Peter’s clinical team (including SLPs and OTs) was in a state of transition between the times of new switch delivery and study completion. This resulted in delays in training of the school team and delays in goal establishment. This transition probably contributed to the disconnect between the school team and the family; Peter’s mother was under the impression that he was using and training with the new switch regularly at school, when in fact it was not used at all in the final few weeks of the study. Additionally, the school team had many problems throughout the
study period with Peter’s Vmax system, and there was often a long waiting period before those problems would be solved. At times when the Vmax was not working, the school team often did not use either of Peter’s switches for classroom activities. These results further support the claims in the literature that a technology that is not appropriate to the user is more likely to be abandoned [36], and that all factors relating to the user, their environment and the tasks they wish to complete must be taken into account in the development and selection process.

3.5 Future Directions

There is much to be learned from Peter’s case regarding our Access Technology Delivery Protocol (ATDP). Firstly, in future studies, changes in health, environment or other factors that may impact the user’s performance with the switch should mandate a reassessment of the user. Secondly, although the protocol aims to involve as many caregivers as possible who will have some interaction with the switch, it is clearly of particular importance to involve those who will be doing the majority of the switch training. It was not clear at the beginning of the study that the majority of Peter’s switch training would occur at school and thus the exclusion of Peter’s school team from the assessment process was not considered a major drawback. However, this clearly had an impact on the final outcomes of the study. In future work, the ATDP should include a specific requirement for the initial assessment to gather information regarding the parties conducting the switch training and to involve those individuals in the process. Finally, with the above modifications, the ATDP should continue to be tested with more individuals to improve the process and build the evidence base for the delivery of response efficient access solutions.
Chapter 4

Conclusion

4.1 Summary of Contributions

In the opinion of the author, this thesis has made the following original contributions:

1. The development and refinement of an Access Technology Delivery Protocol based on response efficiency theory that has the flexibility required to be used with individuals with multiple and severe disabilities.

2. Demonstrated that a response efficient device is likely to be appropriate for the user, based on the ISO 9241-9 definition of appropriateness.

3. Demonstrated that an appropriate access technology can have a positive impact on goal attainment and be associated with improvements in participation for individuals with multiple and severe disabilities.
4.2 Future Work

4.2.1 Enhancement of the ATDP Initial Assessment

There are two major areas identified in the case studies where the ATDP could be improved. Firstly, as demonstrated in Peter’s case, the initial assessment should include questions regarding who will be the primary person or persons responsible for switch training. Furthermore, that person should be involved in the ATDP process from the earliest point possible. Second, changes in the user’s health, environment or other conditions that could impact the individual’s ability to make use of their new technology should necessitate a reassessment of the individual, and this should be stipulated in the protocol. A modified model of the ATDP to incorporate these changes can be seen in Figure 4.1.

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Figure 4.1: Modified Access Technology Delivery Protocol
4.2.2 Enhancement of the Outcome measures

Second, a quality of life measure that is more directly related to the impact of access or assistive technologies, could enhance the quality of information gathered by that measure. Therefore, replacement of the LIFE-H questionnaire with something such as the Family Impact of Assistive Technology Scale should be considered.

4.2.3 Enhancement of the follow-up process

Many of the differences seen in Peter’s outcomes as compared to those of Adam and Jessica related to the amount and quality of training he had with his new switch, which was highly dependent on having skilled training partners. In the current protocol, the switch training process is left uncontrolled. A standardized approach to switch training, designed and developed by a person with expertise in the field, could help to minimize the effects of different training partners. Requiring a full-time specialist for switch training would not be practical. However the development of a standard switch training protocol that could be individualized to be used with parents, teachers or whomever the user’s common training partner would be, could result in the provision of better switch training overall and, as a result, more positive outcomes.

4.2.4 Increase in testing

Thus far, the ATDP has only been tested with 3 individuals. In order to fully validate its use, testing should continue to be done with greater numbers of participants from as wide a variety of backgrounds as possible.
Bibliography


Appendix A

Client Information Questionnaire
**Before asking the following questions, this statement is read to the caregiver:**

The following questionnaire takes approximately 30 minutes to complete. Is now a good time?

*If parent/caregiver prefers a later time, ask:* When would be a good time for me to contact you?

All client and caregiver information will be kept confidential. If the information gathered through the following questions is used in a dissertation or publication in the future, the client’s or his/her caregivers’ real names or contact information will not be used.

Do you give verbal consent to TOM CHAU (Primary Investigator) or LESLIE MUMFORD (Co-Investigator) at Bloorview Research Institute to use this information for research and publication purposes?

Date:

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
</tr>
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<tbody>
<tr>
<td>1. How old is the participant?</td>
<td></td>
</tr>
<tr>
<td>2. Does he/she live at home?</td>
<td></td>
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<tr>
<td>3. Who is the primary caregiver (e.g. mother, father; not the name of caregiver)?</td>
<td></td>
</tr>
<tr>
<td>4. Who are the secondary caregivers? (e.g. mother, father; not the name of caregiver)?</td>
<td></td>
</tr>
<tr>
<td>5. Does he/she receive special education services (for child participants only)?</td>
<td></td>
</tr>
<tr>
<td>6. What is his/her education (grade) level?</td>
<td></td>
</tr>
<tr>
<td><strong>PHYSIQUE</strong></td>
<td></td>
</tr>
<tr>
<td>7. Diagnosis (type of disability - Please answer thoroughly and include medical names)</td>
<td></td>
</tr>
<tr>
<td>8. Date when disability first started (or when you first noticed it)</td>
<td></td>
</tr>
<tr>
<td>9. Over the years has his/her functionality progressed or deteriorated?</td>
<td></td>
</tr>
<tr>
<td>10. What is his/her comfortable posture?</td>
<td></td>
</tr>
</tbody>
</table>
### 11. Does he/she have upper body control?

- Trunk
- Neck
- Arms
- Fingers
- Eyes

### 12. Does he/she have involuntary body movement?

- Is it frequently or occasionally?

### 13. Does he/she have spasms?

- Is it frequently or occasionally?

### 14. Does he/she experience seizures?

- Are there factors that trigger a seizure for him/her?

### COGNITION

15. Does he/she understand cause and effect? (e.g., if I press a push button and he will hear a beep sound and I repeat this several times, will he/she understand what is causing the beep?)

### 16. Can he/she follow cues?

- What are those cues?

### SENSORY

17. Vision

- Has he/she been tested for vision acuity? When?
- What do you (as the primary caregiver) think about his/her vision acuity?

18. Hearing

- Has he/she been tested for hearing acuity? When?
- What do you (as the primary caregiver) think about his/her hearing acuity?
### MOTOR

19. Can he/she control the movement of any of his body parts reliably?
   
   What are they?

20. Has he/she ever used any of the following switches?
   
   - Push button
   - Head switch
   - Chin switch
   - Sip and puff

   Has he/she used any other switches? Please name.

21. For the particular switch or switches that he/she has used, how was his/her:
   
   - Accuracy
   - Operation speed
   - Fatigue

22. What problems did he/she have with those switches?

23. Does he/she experience increased fatigue as the day progresses?
   
   - What kind of activities does he/she find difficult to perform later in the day?
   - What time of day is his/her functionality at his/her best to try new switches?

24. Is his/her mouth usually closed or open?
   
   - How fatiguing is it for him/her to open and close the mouth?

### COMMUNICATION

25. Is he/she verbal at all?

26. Current means of communication?

27. Can other people understand him/her or only you can?

28. Is he/she able to make facial expressions? Which one of the following can he/she do?
   
   - Eye blink
<table>
<thead>
<tr>
<th>Eyebrows</th>
<th>Smiling</th>
<th>Tongue protrusion</th>
</tr>
</thead>
</table>

29. Was he/she able to communicate better at a younger age?
   When?
   How?

30. If you answered 'Yes' to the last question, why do you think he/she has lost that communication?

31. What are his/her signs of:
   Joy
   Excitement
   Pain/ discomfort
   Boredom

32. Would you like to be contacted for future studies in our research group? Please note that if you say 'yes' to this question, the participants age and diagnosis may be shared with other researchers in our group. All other information will be kept strictly confidential.

If you agree, please provide an email address or phone number that you can be reached at.
Appendix B

Modified Goal Attainment Scale
### Modified Goal Attainment Scale

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<thead>
<tr>
<th>GAS Score</th>
<th>Achievement Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>-3</td>
<td>Much much less than expected (Worse than Present Level)</td>
</tr>
<tr>
<td>-2</td>
<td>Much less than expected (Present Level)</td>
</tr>
<tr>
<td>-1</td>
<td>Somewhat less than expected (Making Progress)</td>
</tr>
<tr>
<td>0</td>
<td>Expected Level (Program Goal)</td>
</tr>
<tr>
<td>+1</td>
<td>Somewhat better than expected</td>
</tr>
<tr>
<td>+2</td>
<td>Much better than expected (Longer term goal)</td>
</tr>
<tr>
<td>+3</td>
<td>Much much better than expected</td>
</tr>
</tbody>
</table>

Figure B.1: Modified Goal Attainment Scale
Table B.1: Sample goal using GAS for Adam using the Smile Switch

<table>
<thead>
<tr>
<th>Goal Area</th>
<th>Reading books on the computer and using the Smile Switch to turn the page</th>
</tr>
</thead>
<tbody>
<tr>
<td>-3: Much, much less than expected</td>
<td>Adam will no longer participate in computer reading activities</td>
</tr>
<tr>
<td>-2: Much less than expected (Present Level)</td>
<td>Adam just received the smile switch. He requires verbal prompting 70% of the time to activate the switch in a 20 minute computer session.</td>
</tr>
<tr>
<td>-1: Somewhat less than expected</td>
<td>Adam requires verbal prompting 50% of the time to activate the switch.</td>
</tr>
<tr>
<td>0: Expected level (Program Goal)</td>
<td>Adam requires verbal prompting 30% of the time to activate the switch.</td>
</tr>
<tr>
<td>+1: Somewhat better than expected</td>
<td>Adam requires verbal prompting 15% of the time to activate the switch.</td>
</tr>
<tr>
<td>+2: Much better than expected</td>
<td>Adam can independently activate the switch to turn the page on the computer.</td>
</tr>
<tr>
<td>+3: Much, much better than expected</td>
<td>Adam can independently activate the switch to choose, start, turn the page and stop a story on the computer.</td>
</tr>
</tbody>
</table>
Appendix C

LIFE-H for Children - Short Form
Figure C.1: Sample section from the LIFE-H for Children - Short Form [13]
Appendix D

Quebec User Evaluation of Satisfaction with Assistive Technology
Figure D.1: Sample section from the QUEST 2.0 [9]